

Medical Progress

Screening for Developmental Disabilities

CAROL FOSTER, PhD; DEBORAH DURAN-FLORES, MSpEd, OTR; KENNETH W. DUMARS, MD, and
STANLEY STILLS, MS, MFCC, Orange, California

Developmental disabilities are responsible for a combination of severe physical, mental, psychological and social deficits. They develop before age 22 years and involve a little more than 1% of the population. Screening for developmental disabilities is the first step in their prevention. Various screening instruments are available for use throughout the developmental years that are designed to detect the wide variety of developmental problems that interfere with a developing person's optimal adaptation to his or her environment. The screening instruments must be inexpensive, reproducible, widely available and cost effective to the child, family and society.

(Foster C, Duran-Flores D, Dumars KW, et al: Screening for developmental disabilities [Medical Progress]. West J Med 1985 Sep; 143:349-356)

Developmental disabilities are estimated to produce severe impairments in a little more than 1% of the population.¹ Many studies have shown improved outcomes for children with or at risk for developmental disabilities who are provided treatment at very early stages.² Because pediatricians and family practitioners are among the few professionals who, as a group, see almost all infants and young children, they play a major role in the early diagnosis of developmental disabilities. Their role in screening for many childhood conditions (for example, the federally mandated Early and Periodic Screening, Diagnosis and Treatment [EPSDT] program on screening for health assessments) is well understood, but their role in screening a child at risk for developmental disabilities is not as well defined. For a program to be effective, the screening procedures should be available for everyone at risk in the population. Ideally, the screening should be accomplished at a single contact with a child or family and with a minimum of cost and time. Unfortunately, a one-time screening effort for developmental disabilities is ineffective because the disabilities may emerge at any time during the developmental period, including the adolescent years, and present with diverse symptoms. A brief overview of the definition of developmental disabilities indicates the complexities of comprehensive screening.

Defining Developmental Disabilities

The category of developmental disabilities was first established in 1970³ to encompass a broad spectrum of disorders, all of which result in children developing more slowly than their peers, acquiring fewer skills than their peers and re-

quiring extensive support systems throughout their lives. To be eligible for services under the Developmental Disabilities Act, a person must fit the definition of developmentally disabled:

The term 'developmental disability' means a severe, chronic disability of a person which

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the person attains age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in three or more of the following areas of major life activity:
 - a. Self-care,
 - b. Receptive and expressive language,
 - c. Learning,
 - d. Mobility,
 - e. Self-direction,
 - f. Capacity for independent living,
 - g. Economic self-sufficiency, and
5. Reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services that are of lifelong or extended duration and are individually planned and coordinated.³

The above definition is a functional one because it identifies how a person carries out daily activities. While each state must follow this definition to obtain the federal funds, some states use slightly different versions. For instance, California uses a combination of categorical (describing the type of disability) and functional approaches. That is, a person with a substantial functional limitation is eligible only if she or he has mental retardation, cerebral palsy, epilepsy, autism or a related neurologic disability.⁴

From the Division of Developmental Disabilities and Clinical Genetics, Department of Pediatrics, University of California, Irvine, Medical Center, Orange.
Reprint requests to Kenneth W. Dumars, MD, Department of Pediatrics, UC Irvine Medical Center, 101 The City Drive S, Orange, CA 92668.

ABBREVIATIONS USED IN TEXT

CHDP = Child Health and Disability Prevention
DDST = Denver Developmental Screening Test
EPSDT = Early and Periodic Screening, Diagnosis and Treatment
IEP = Individual Educational Plan
PKU = phenylketonuria

Purpose of Screening for Developmental Disabilities

In this article we provide an overview of a broad-based screening program and describe the importance of a physician's role in that program.

Screening is the application of a simple accurate method for determining which children in a population are likely to be in need of special services to develop optimally. After screening, one can determine which persons should receive more extensive, more intrusive or more costly diagnostic procedures. Screening procedures should not be viewed as diagnostic, they simply divide a population into those who need diagnostic work and those who are not at risk for a condition. Diagnosis determines the extent and, in some cases, the cause of a disorder and is useful for making placement decisions.⁵

A broad-based screening program must include the functional, categorical and etiologic approaches. If only one or two of these approaches are used, eligible children may not be identified until major delays have occurred. Table 1 provides examples of how children at risk for different conditions may or may not be identified if the screening program assumes only a single definition or orientation.

For example, if one screens only for significant limitations, then phenylketonuria (PKU) will not be discovered until irreparable brain damage has occurred. Also, if one screens only for specific etiologic conditions, then many children with mental retardation, language delay and other conditions of unknown cause would be missed.

Characteristics of Screening Programs

Standard screening procedures should share common characteristics whether they are to screen for tuberculosis or

for developmental disabilities. First, the screening procedures should be less costly in time, materials and other resources than the diagnostic procedures. If the resource requirement is essentially equal, then a professional should simply use an accurate diagnostic procedure.

Screening procedures should also be simple. An extremely difficult or painful procedure cannot be justified for every child when only 1 out of 10,000 may have the condition. Conversely, asking a 5-year-old child to respond to the Snellen E chart is simple for both the child and the professional.

A comprehensive program should also incorporate screening for conditions other than developmental disabilities. Including biomedical conditions such as sickle cell disease, psychological problems such as attention-deficit disorder and sociocultural problems such as child abuse greatly enhances the screening program.

Screening is appropriate whenever age of onset and duration of process aggravate or worsen the outcome. As with any behavioral trait, early identification or preventing its occurrence lessens the sequelae of complications. Just as proper eating habits ameliorate the occurrence of obesity and not starting to smoke is easier than stopping, early identification of those mechanisms responsible for failure of attentiveness or learning improves outcome. Medicine has learned that treating a case of tuberculin conversion is easier than waiting for the development of disseminated disease. Placing a newborn on a low phenylalanine diet prevents the occurrence of the devastating consequences of uncontrolled phenylalanine levels.

Related to intervention is the cost effectiveness of the screening procedures. Relatively costly procedures for extremely rare disorders need to be considered carefully. The cost of lead screening on the East Coast has been considered a worthwhile investment because of the incidence of lead poisoning there (Table 2). It is unclear whether or not this is an appropriate activity in many western states where young children's access to lead is limited. However, screening tests adequate for detection should be inexpensive, easily repli-

TABLE 1.—How a Screening Program Can Be Affected By the Definitional Approach Taken

Condition Identified	Type of Definition		
	Functional*	Categorical	Etiologic
PKU	Discovered only after irreparable brain damage has occurred. A child with PKU is identified only when functional limitations are apparent.	Discovered only after irreparable brain damage has occurred. A child with PKU is identified only when mental retardation is apparent.	Discovered through a newborn screening program; damage can be prevented.
Mental retardation	Discovered through screening for functional limitations.	Discovered through screening for functional limitations.	Many etiologic conditions result in mental retardation, but if screening is done only on an etiologic basis, many are missed.
Substantial limitation in language and self-care associated with neglect and not associated with mental retardation, cerebral palsy, epilepsy or autism	Discovered through screening for functional limitations.	Discovered through screening but may not be eligible.	Probably not discovered by screening according to cause.
Lead poisoning	Discovered only after irreparable brain damage has occurred; a person with lead poisoning is identified only when functional limitations are apparent.	Discovered only after irreparable brain damage has occurred. A person is identified only when mental retardation is apparent.	Discovered through lead screening; further damage can be prevented.

PKU = phenylketonuria

*The functional approach is as laid out in the Developmental Disabilities Act of 1970.³ In the State of California, functional limitations must be associated with mental retardation, cerebral palsy, epilepsy and autism.

cated and capable of being conducted by a health, educational or psychological assistant. The screening test should be accompanied by a minimum of false-positive and false-negative results. False-negative results (failing to refer persons who have the condition) should be avoided for conditions that are potentially devastating, such as those identified in biochemical newborn screening. Conditions that may result in negative labeling (poor environment) may require a more conservative approach to referral and have more false-negatives. In the latter instance, continued surveillance by a physician is important.

Screening tests imply surveillance of a large at-risk population, together with accurate diagnostic capabilities and effective intervention modalities or strategies. There are situations wherein screening is most successful within a limited population. For example, Tay-Sachs and sickle cell diseases occur in fairly circumscribed groups. A crucial decision is when the screening program should be applied. For example, screening for PKU, galactosemia and hypothyroidism during the newborn period identifies those at risk during the early period when treatment is most effective rather than, for example, screening at the preschool ages. Unless there are earlier clinical symptoms, screening for vision and hearing deficits coincides nicely with children's visits to physicians just before entering school. Referrals for further testing and intervention can follow. Using the latest technology, which will soon be available, screening for Huntington's disease during the newborn or early years is inappropriate for we have nothing to offer those who may be carriers and thus will ultimately be affected.

Screening for behavioral and cognitive end points must be interpreted very cautiously. Screening for development must be a collaborative venture between those testing a child and the child's guardian, usually the parents. A child who generally functions within normal limits may score in the questionable range for reasons of ill health, emotional stress, culture or language barriers. Intervention in the event that a child does not test within the normal range is carried out only after due collaboration with parents, health care providers or educators. This again emphasizes the fact that screening in no way implies a diagnosis, or that it should immediately be followed by an intervention or a prognostication. It should only trigger a mechanism in which a full evaluation of that child is done, including input from parents, guardian caretakers, educators or day-school personnel.

Screening for PKU in California provides an example of

procedures that meet these considerations. By screening at birth in the hospital, the program reaches essentially all newborns. In California from October 3, 1980, to August 1, 1985, which includes 1,585,143 tests, there were no missed cases.⁷ It requires little effort on the part of hospital staff. All infants with elevated phenylalanine levels are identified by the screening test; 1 out of 34 with an initial positive screen has classical PKU. The cost is \$24 per infant tested, which is low when compared with the cost of at least \$40,000 per year for adults with untreated PKU.¹ Finally, early diagnosis is extremely important. An effective dietary treatment can be instituted immediately, resulting in the child's maintaining normal intellectual functioning. This is in contrast to children untreated for even the first year of their lives, whose mental development will be retarded. There is a direct relationship between the length of time a child is untreated and the decrease in intellectual functioning.^{8,9} Thus, PKU screening is available to all newborns and is accurate, simple, inexpensive and results in early effective treatment.

Recommendations for a Physician's Role in Screening

The physician's role in screening is especially important. As a provider who has regular contact with the family, the physician can monitor a child's development through routine screening. The role of physicians in preventing the occurrence of a developmentally disabling condition will be described at three developmental stages: preconceptual, prenatal and postnatal.

Preconceptual

The health of a newborn is to some extent related to the state of the mother's health. Certain safeguards for a newborn infant can be undertaken by the mother. It is hoped that the mother is in optimal health before and during her pregnancy. Table 3 lists those situations that increase a mother's risk for complications including the birth of a handicapped infant. A physician may wish to screen women for these factors and counsel them accordingly.

Though a mother affected with one of many chronic diseases can deliver a normal infant, there are disorders such as hypertension, diabetes, heart or renal disease and the like that increase her risks for complications. Optimally, before pregnancy all mothers should receive the rubella vaccine or have serologic evidence of rubella immunity (or both). The pres-

TABLE 2.—*Regional Screening for Lead Poisoning of Children Who Required Pediatric Management, October 1, 1980, Through September 30, 1981**

Region†	Total Screening	Total Requiring Pediatric Care	Percentage (%)
I Conn, Mass, RI—6 programs	51,282	1,622	3.16
II NJ, NY—14 programs	171,728	8,786	5.12
III Del, Md, Pa, Va, Washington, DC—12 programs	84,195	3,722	4.42
IV Ga, Ky, SC, Tenn—4 programs	47,631	614	1.29
V Ill, Ind, Mich, Ohio, Wis—15 programs	108,430	5,087	4.69
VI Ark, La, Tex—4 programs	48,944	571	1.17
VII Iowa, Mo, Neb—5 programs	19,487	1,481	7.60
IX Calif—2 programs	4,033	9	0.22

*From the Centers for Disease Control, 1982.⁵

†No data are available for Region VIII.

ence of genetic disorders and maternal age influence the risks of being delivered of a handicapped infant. It is useful to know the blood and Rh type of the mother and, if the mother is blood type O, Rh negative or both, the father should be tested. In selected populations it is advisable for couples to have reproductive testing for sickle cell disease (in blacks), thalassemia (in Asians and Mediterranean population groups) and Tay-Sachs disease (in Jews).

Prenatal

Wilson¹⁰ has listed genetic and environmental causes of developmental defects, as shown in Table 4.

A note of caution is necessary in interpreting this table. A developmental defect differs from a developmental disability. For example, cleft lip-cleft palate is a developmental defect, but in isolation rarely produces a developmental disability.

Earlier we mentioned the desirability of screening for the hemoglobinopathies and Tay-Sachs disease in appropriate population groups. As part of preconceptual or prenatal care, one should obtain a brief pedigree, inquiring specifically

about fetal loss, malformations, mental retardation, short stature, myopathies and neuropathies and common disorders such as cystic fibrosis, Huntington's disease and other late-onset disorders. Based on this information and parental age, the following families must be notified about the availability of prenatal diagnosis for genetic disorders:

- The mother will be 35 years or older or the father will be 55 years or older at the time of the child's birth.
- Either parent has had a previous child with Down's syndrome or another chromosomal abnormality.
- There is a history of a relative with a proved possibly heritable chromosomal anomaly or mental retardation.
- The couple has a history of two or more miscarriages or infertility.
- Either parent carries a balanced chromosome rearrangement (inversion or translocation).
- There is a history of a congenital malformation in either parent or in a previous child.
- There is a family history of a neural tube defect such as spina bifida or anencephaly.
- Both members of the couple are carriers of an autosomal recessive disorder, such as Tay-Sachs or sickle cell disease, thalassemia or PKU.
- The mother is a known or possible carrier of an X-linked condition, such as Duchenne's muscular dystrophy, hemophilia A and X-linked mental retardation.
- Either parent is affected with or has been shown to carry the gene for an autosomal dominant condition, such as achondroplasia, Marfan's syndrome, tuberous sclerosis or neurofibromatosis.
- The mother has insulin-dependent diabetes mellitus, requires medication for epilepsy or has a history of other possible teratogenic exposure, such as rubella, x-ray or certain drug use during pregnancy.
- The parents are consanguineous (blood-related).
- There is reason to suspect fetal abnormality on the basis

TABLE 3.—High-Risk Obstetric Patients

Socioeconomic
Age, younger than 18 years or older than 34 years
Parity, 0 or more than 4
Marital status, unwed
Below 125% of poverty level
Educational status, less than 12 years
Poor conditions for home delivery
Nutritional
Weight falling outside of standard weight range
Hemoglobin, less than 10 grams per dl
Past pregnancy performance
Difficult labor, prolonged (longer than 24 hours)
Previous cesarean section
History of postpartum hemorrhage
Past pregnancy outcome
Fetal death (infant larger than 500 grams [1 lb 2 oz])
Neonatal death (infant larger than 500 grams [1 lb 2 oz])
Major congenital anomaly (incompatible with extrauterine life)
Low birth weight (less than 2,500 grams [5½ lb])
Three consecutive abortions (less than 500 grams)
Damaged infant (especially neurologic defects)
Medical or obstetric complication, present pregnancy, including but not limited to
Preeclampsia, eclampsia
Genital herpes
Diabetes mellitus
Heart disease
Rh sensitization
Sickle cell anemia
Hemoglobinopathies
Renal disease
Mental retardation as evidenced by one of the following
Previous enrollment in a special education class
Evaluation by a state or federal department of vocational rehabilitation
Evaluation by a state or federal department of mental disabilities
Evaluation by a licensed psychologist
Substantial evidence of inability to manage daily self-care
Mental illness as evidenced by one of the following
Diagnosis from a psychiatrist
Evaluation by a mental health center
Evaluation by a psychiatric hospital

TABLE 4.—Causes of Developmental Defects in Humans*

Defects	Percentage (%)
Known genetic transmission	20
Chromosomal aberration	3-5
Environmental causes	
Ionizing radiation	< 1
Therapeutic	Nuclear
Infections	2-3
Rubella virus	Varicella virus
Cytomegalovirus	Toxoplasma
Herpesvirus hominis	Syphilis
Maternal metabolic imbalance	1-2
Endemic cretinism	Phenylketonuria
Diabetes mellitus	Virilizing tumors
Drugs and environmental chemicals	4-5
Androgenic hormone	Anticonvulsants
Folic antagonists	Oral hypoglycemics (?)
Thalidomide	Few neurotropic-anorectics (?)
Oral anticoagulants	Organic mercury
Maternal alcoholism	
Combinations and interactions	?
Unknown	65-75

*Estimates are based on surveys and case reports in the medical literature.

of other studies (ultrasound, maternal serum α -fetoprotein level or Rh titer).

Within the next 6 months, California will institute a state-wide screening program for neural tube defects using maternal serum α -fetoprotein. This will be voluntary and will be carried out at 15 to 16 weeks' gestation. A blood specimen will be drawn in private offices and clinics and then forwarded to central laboratories. This will identify, in the tested mothers, 80% of the conceptuses affected with neural tube defects. The other 20% will not be detected as the sac on the back is covered with normal skin and will not allow the escape of α -fetoprotein-containing cerebrospinal fluid from the fetus to the amniotic fluid and eventually the maternal serum.

The environmental risks listed in Table 4 are self-evident. We cannot emphasize enough the importance of maintaining adequate medical records, especially those related to environmental mechanisms. In light of our present knowledge, environmental agents are responsible for but a small segment of developmental defects and an even smaller segment of developmental disabilities. However, practitioners must be cautious in prescribing drugs during pregnancy because, for a litigious-minded American public, lack of absolute proof that an agent causes a defect is not an adequate safeguard when a physician is faced with a lawsuit in front of a lay jury. We need only cite the enormous settlements awarded to patients and families who have a history of Bendectin* usage during pregnancy or paternal exposure to Agent Orange. These pending settlements occurred despite the fact that neither of these two agents is clearly identified as being embryotoxic.

*A combination drug by Merrell Dow, each tablet of which contains 10 mg of doxylamine succinate and 10 mg of pyridoxine hydrochloride.

Nonetheless, clear record keeping is essential in documenting the need for any drug, along with adequate information given to patients.

Maternal substance abuse, particularly alcohol, is a significant contributing agent to the occurrence of developmental disabilities in offspring. Fetal alcohol syndrome is estimated to be the third most common cause of developmental disabilities, with a frequency of 1:1,000 to 1:2,000 of live-born infants,¹¹ just a bit less than the incidence of Down's syndrome.

Though recreational and street drugs are not embryotoxic, addicting drugs such as heroin, methadone and so forth certainly produce addiction in newborns and endanger an infant's survival. Cigarette smoking probably does not cause developmental disabilities; infants born to mothers who smoke, however, are often of low birth weight with its attendant risks.

Postnatal

Physicians are the professionals most likely to detect early developmental problems. Table 5 contains recommendations for specific screening tests and their timing from birth through adolescence.

Physicians, or their assistants, should be familiar with these procedures, schedule them on routine visits and monitor each child's development longitudinally. As can be seen from Table 5, there is a variety of screening procedures; they include determinations of cognitive and motor development, nutrition and parenting skills, in addition to a child's physical state (Tables 6 and 7).

If the results of any of these procedures are questionable, the physician should either apply the appropriate diagnostic

TABLE 5.—Recommendations for Screening Tests From Birth Through Adolescence

Age of Person Being Screened: Interval Until Next Exam:	Months								Years							
	Birth 1	1-2 1	3-4 2	5-6 2	7-9 3	10-12 3	13-17 5	18-23 6	2 1	3 1	4-5 2	6-8 3	9-12 4	13-16 4	17-20 None	
Screening Procedures																
History and Physical Examination																
Developmental history and assessment																
Infant/child indicators of high-risk status*	X	
Dubowitz or comparable newborn evaluation†	X	
Evaluation of motor development‡	X	X	X	X	X	
PDQ§ and DDST	X	X	X	
Dental assessment	
Nutritional assessment	
Health education	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Vision Screening																
Snellen or equivalent visual acuity test	X	X	X	X	X	X	
Clinical observation	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Hearing Screening																
Audiometric	X	X	X	X	X	X	
Nonaudiometric	..	X	X	X	X	X	X	X	X	X	
Laboratory Tests																
Hematocrit or hemoglobin	X	..	X	..	X	X	X	..	X	X	X	
Urine dipstick or urinalysis	X	X	X	X	X	
Newborn screening	X	
Free erythrocyte protoporphyrin	
May be done only if health history warrants																
DDST = Denver Developmental Screening Test, PDQ = prescreening developmental questionnaire																
*See Table 6 for full description.																
†From Dubowitz and Dubowitz. ¹²																
‡See Table 7.																
§From Frankenberg et al. ¹³																
From Frankenberg et al. ¹⁴																

procedures or refer to the appropriate agency. The decision for referral depends on the state and how services are provided. In California, referral to a regional center for diagnostic testing initiates the entry into the service system. Other states have other systems. In general, a physician should have colleagues in physical therapy, occupational therapy, social work, nutrition, dentistry, ophthalmology, audiology, speech and language, education and psychology who can co-operate in diagnosis and the development of intervention strategies.

Another important role a physician provides is communication with the family. By treating screening as part of routine pediatric care, the physician will be communicating with the

family on the child's development and will be orienting them towards prevention efforts. As the child grows, parents and physician will discuss motor development, the child's response to parents and the use of language. Parents are excellent observers of their children,¹⁷ and discussion with them can augment the physician's perception of a child. In addition, discussions on development will make the need for further testing more understandable in those infrequent instances when it is necessary. Incorporating the parents' observations into the physician's screening results will involve the parents in the decision. More familiarity with development also provides a better basis for encouraging questions and discussion.

A related responsibility of the physician is preparing parents for the diagnostic testing and possible intervention. Parents should be informed of what to expect, how long it will take, whether or not pain is involved, what information will be obtained and so forth. A few minutes of discussion on a procedure such as the auditory evoked potential can greatly reduce apprehension and promote the physician's rapport with the family. The preparation of parents promotes their ability to prepare their child. Better prepared and calmer parents result in calmer children, thus facilitating more accurate results on many diagnostic tests.

Schools

The physician's involvement with the educational system is important because of the federally mandated screening program. Nationally, the federally mandated EPSDT pediatric screening program is designed as an ongoing federally funded source of medical checkups and care for all persons, 0 to 21 years of age, enrolled in a state medicaid program, namely, that for low-income families.

California operates its version of this program, Child Health and Disability Prevention (CHDP), which, as of 1981, includes EPSDT services and state-supported screening only, not diagnosis and treatment, for "income-eligible, non-MediCal" children.

TABLE 6.—Criteria for Eligibility of High-Risk Infants for Regional Center Intervention Services*

Medical Factors
Prematurity (less than or equal to 32 wk)
Postmaturity (greater than or equal to 44 wk)
Low birth weight (less than or equal to 1,500 grams)
Small for gestational age (Lubchenco Scale)
Assisted ventilation with persistent respiratory instability, including recurrent apnea
Prolonged hypoxemia
Prolonged hypoglycemia, hypocalcemia
Hyperbilirubinemia (greater than or equal to 15 mg per dl)
Seizures or transient neurologic signs (positive or negative) in first 5 days of life
CNS hemorrhage, grades 2-4
Confirmed correlating infections of the CNS (meningitis, encephalitis)
Multiple congenital anomalies requiring special services
History of maternal chemical exposure (alcohol, hydantoin, warfarin)
Abnormal neurologic findings in premature infants
Not significant if
atypical tone
asymmetry
startles and/or tremors
Significant if combined with
lack of or inconsistent visual pursuit
decreased popliteal angle
decreased mobility
Clinical/Behavioral Factors
Persistent feeding problems (mechanical)
Persistent inability to self-calm
Erratic sleep-wake patterns
Persistent tonal problems
Continued evidence of delay in one or more developmental areas
Social/Environmental Factors
Poor maternal-infant attachment
Prior family history of abuse/neglect (parents, other siblings)
Neonatal addiction or maternal history of substance abuse
Mother's medical or mental condition of a nature to require professional supervision and support to assure necessary child care (severe cerebral palsy, mental retardation, depression, alcohol abuse)
Maternal age is 16 years or younger†
Lack of or inadequate use of support systems (church, parents)†
In the opinion of an interdisciplinary team—such as a hospital discharge planning team or a Regional Center Developmental Disabilities intake team—the infant is considered to be at high risk for becoming developmentally disabled.

CNS = central nervous system

* Report of the Association of Regional Center Agencies Prevention Task Force.¹⁶

† May not be used as a single criterion.

TABLE 7.—Normal Ages of Appearance and Disappearance of Neurologic Signs Peculiar to Infancy*

Response	Age at Which Normally Appears	Age at Which Normally No Longer Obtainable
Spontaneous stepping	Birth	2-6 wk
Positive supporting (neonatal type)	Birth	3-6 wk
Crossed extension (allongement croisee)	Birth	1-2 mo
Trunk incurvation	Birth	1-2 mo
Moro reflex	Birth	1-3 mo
Redressement du tronc	Birth	Variable
Leg flexion in vertical suspension	Birth	4 mo
Rooting	Birth	3-4 mo awake, 7 mo asleep
Palmar grasp	Birth	6 mo
Adductor spread of knee jerk . . .	Birth	7 mo
Plantar grasp	Birth	9-10 mo
Tonic neck patterns (impossible) . . .	2 mo	5 mo
Landau reflex	3 mo	12-24 mo
Neck righting reflex (impossible) . .	4-6 mo	12-24 mo
Positive supporting (weight bearing)	6 mo	(persists)
Parachute reaction	8-9 mo	Variable

* From Paine.¹⁵

The national EPSDT screening model promotes an interest in identifying recognizable pediatric disorders that interfere with health and development. The screening periodicity chart (see Table 5) indicates that a developmental history and assessment is a part of health-assessment procedures required of an examiner at each of the age levels, from birth through 21 years. All practitioners can obtain developmental data from simple techniques and communication skills.

A Denver Developmental Screening Test (DDST)¹⁴ is the standard tool used by pediatric nurse practitioners and physicians to assess development in children from birth through age 6 years. Beyond 6 years of age, medical tests, clinical observations, home-school psychosocial adaptation and knowledgeable judgment are the health professional's tools of developmental assessment. The newly revised DDST, the DDST-R, is less time-consuming than earlier versions. Specifically, 12 items or fewer are all that are necessary to obtain a result on children up to the age of 6 years. Even more simply, a prescreening developmental questionnaire¹³ can be given to parents to complete in a few minutes. It is a "pre-screening" tool designed to select those children who should have a complete DDST. This questionnaire is extremely short and simple and uses parental reports. It can discriminate developmental lags and suggest more detailed screening. In later ages, collaboration among health and education professionals and parents is essential for an effective and efficient use of a physician's time. While most abnormalities are minor, pediatric nurse practitioners, on screening students in schools, do regularly refer children with greater health and developmental manifestations for possible diagnosis and treatment.

For a child identified after age 6 years, referrals to a special education program originate primarily from teachers, parents, nurses and classroom aides, but at present relatively few from physicians. A typical "child-study team" might be the first level of response to a referral. Consisting of an administrator, a registered nurse, the child's classroom teacher and an appropriate professional evaluator, the team will review a child's level of performance and determine possible eligibility for special education services. If so determined, a second-level assessment strategy will be orchestrated to obtain various evaluations and pertinent information for use in deciding on the most appropriate special education services. Participants on this latter team may include school personnel, outside physicians and clinics, therapists and parents. Following attaining their findings, an Individual Education Plan (IEP) is written by school district personnel, the classroom teacher, parents and others who will delineate the following: the special services required, such as diet, transportation, nursing care; the classroom environment for placement (a special day class, a resource specialist), and teaching objectives and methods planned for an individual child—that is, academic, vocational, sign language or braille. An annual review and a three-year follow-up IEP meeting shall follow to evaluate case management.

The message to physicians from professionals in the fields of early childhood education and special education is to be aware of what a public school can and cannot do, along with what a medical practitioner can and cannot do. Basically, local school districts are able to take referrals on a child and determine a student's eligibility for certification as a "child with exceptional needs" for any child between the ages of

birth and 21 years. They can also coordinate this process for the child and parents.

The physician can request an assessment of the child's performance and eligibility for "special services" by contacting a county Office of Education, local school district office or a school principal. A physician should look with sensitivity and scrutiny at a child's developmental history and current state and should engage the child *and* the parents in obtaining information to document physical and behavioral elements of each young patient. Physicians can cooperate by communicating via records and personal correspondence to schools, professionals and parents and can become providers of service in the state EPSDT program. Physicians cannot make promises to parents of educational services and special education placement and cannot be negligent by excusing parental concerns and clinically suggestive signs as "something the child will grow out of."

Concerned professionals should make a concerted effort toward an ongoing exchange of information about possible and known exceptional needs of children. The treatment and education of a child with special needs of a physical or a mental nature require the roles of various personnel. Unless all professionals share information and decisions for appropriate intervention, optimal comprehensive care will be unlikely.

Characteristic of uncoordinated client activities are fragmented interventions, gaps in service delivery, costly duplication and ill-advised services, poor child adaptation and parental and professional frustration. A team approach can guard against such problems and ensure that each child is given the opportunity to develop to his or her maximal potential.

Measures of Effectiveness

Evaluating any major social program such as screening for developmental disabilities has some major problems. We propose three general categories for evaluating the effectiveness of screening programs: quality of life, the incidence of developmental disabilities and the cost to society. These range from extremely subjective to quite objective. The most subjective, but perhaps the most important, is improved quality of life for a person and family. While having a developmental disability does not reduce the worth of a person, most people would agree that a developmental disability creates many personal, family and societal problems. Weikart¹⁸ reported a reduction in several major social problems, including teenage pregnancy, unemployment, detention and arrest and welfare assistance for children who had been in a Head Start program 14 years earlier.

Another effectiveness measure that is more scientific but still difficult to obtain is the incidence of developmental disabilities. Determining the reduction in incidence of discrete conditions such as infants with rubella syndrome is complex but can be done with considerable accuracy.¹⁹ The problems with ascertaining decreases in developmental disabilities are exacerbated by several issues. First, developmental disabilities represent a collection of conditions of both known and unknown causes. Due to the different definitions, this collection changes from state to state and even with the diagnostic instrument used. This changing definition creates difficulties in making comparisons across locations and time.

Another difficulty in evaluation is that the definition is relatively new. Since the category was created in 1970, there are no longitudinal data available. Related to this is the fact that because more money and more programs are available for persons with this diagnosis, more are identified.

Still another difficulty is presented by the fact that developmental disabilities can emerge any time during the developmental period. Thus, determining the counts at times when infants and children can be more easily evaluated, such as in screening for PKU at birth, may miss many children affected with other disabilities.

A more concrete measure of effectiveness can be found in ascertaining the cost of various conditions to the state or to the family. All states except two have mandatory screening for PKU, which affects about 1 in 17,000 births. In California, about 20 to 25 cases are detected each year.⁷ Since 1966 when the program began, there has not been a single admission to the state hospital system. A conservative cost-benefit analysis shows that about \$7 are saved for every dollar spent.⁷ Estimates of how much the care of a child with developmental disabilities costs above that for a child without this condition are available. For example, according to the California State Council on Developmental Disabilities, it costs \$360 per month to keep a child of 3 years at home (James Shorter, Executive Director, written communication, August 1984). The cost varies with size of family, age of child and gross income. If a child has a developmental disability and is placed out of the home, the cost can be as high at \$6,000 per month (J. Shorter, written communication, August 1984).

The effects of screening and early intervention have also been documented through cost analyses. Children who received two years of preschool saved more than seven times the cost of the preschool for their public education compared with a matched control group.¹⁸ Wood²⁰ analyzed costs and found that the cost of education for 940 multiply handicapped children depended on the age at which intervention was started. The cost was \$37,273 for children who began programs at birth, compared with \$45,816 for those who started at age 6 years.

The human impact is even more important than the financial aspects. The High/Scope Education Research Foundation found that children in the Head Start program experienced changes that were evident even after 12 years of public school. These children were more likely to finish high school, get a job, enroll in postsecondary education and score well on tests of functional competence than their matched peers who had not attended Head Start.¹⁸ They were less likely to require special education, be arrested, be on welfare or become pregnant during the teen years. Other studies have shown changes in intelligence,²¹ ability to adapt to regular education²² and the ability to be self-supporting.^{23,24}

Another area where early intervention has proved to be quite effective is in follow-up programs for high-risk infants from neonatal intensive care units. In California where these projects have been conducted on a pilot basis, there are significant reductions in child abuse, in the length of the original hospital stay and in the rate of readmission to hospital.²⁵

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